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ABSTRACT

Demographic and background characteristics, pre-adoption motivation, and post-adoptive adjustment of 20 British families who had, among them, adopted 23 mentally retarded children were explored through semi-structured interviews and questionnaires. Children in the sample had been in their adoptive homes an average of 17 months; 48% were under 5 years old. Twenty mothers were interviewed in their homes, either alone or with the father; data from mothers alone was reported. A 10-item mutiple-choice questionnaire assessed family functioning following placement. A 285-item true-false Questionnaire on Resources and Stress (Holroyd) was subsequently completed and returned by all families. General characteristics of the sample indicated that adopters of mentally retarded children are familiar with the handicap, are likely to be of middle-class background, and adopt for a variety of reasons, including biological infertility, religious conviction, and personal/professional experience with the handicap. Among suggested conclusions was that adoptive families may experience less stressful adjustment than biological families of retarded children. (The literature on families who adopt mentally retarded children, as well as on family reactions to biologically borne handicapped children, is reviewed,) (JW)

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FAMILIES WHO ADOPT MENTALLY RETARDED CHILDREN:

WHO, WHY, AND WHAT HAPPENS

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Paper presented at the 17th annual Gatlinburg Conference on Research in Mental Retardation and Developmental Disabilities, Gatlinburg, Tennessee, March 7-9, 1984. Preparation of this paper was supported, in part, by a faculty development grant from St. Mary's College of Maryland.

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FAMILIES WHO ADOPT MENTALLY RETARDED CHILDEN: WHO, WHY, AND WHAT HAPPENS

Although both psychologists and sociologists have studied families with retarded children for several decades now, it has become commonplace for recent reviews to suggest that we still know little about the functioning of such families (Crnic, Friedrich & Greenberg, 1983)

Sometimes this knowledge gap is blamed on the dearth of studies in this particular area (Crnic, et al, 1983), and sometimes on the field, in general, which has failed to focus its efforts on combining the study of the individual within the family ecological system (Belsky, 1981; Lerner & Spanier, 1978). Both developmental psychologists and family sociologists have been faulted for not engaging in the sort of cross-fertilization that would produce a vigorous interdisciplinary approach to the study of families with mentally retarded children.

Recent work in the field has attempted to address these criticisms by focusing on the retarded child as a member of a dynamic family unit which is itself a member of a still larger dynamic social/economic/political network (e.g., Farber, Farran in this volume). This work will undoubtedly begin to prove fruitful as we develop models that incorporate the complex interaction of individuals with family members and family units with other societal institutions and networks.

The present work, however, is a reformulation in a different sense. It does not take a broad ecological approach to the study of families, but it does depart from the traditional stress models that prevail when studying families with retarded children. Because the



families of interest, those who have adopted, rather than biologically borne retarded children, undergo a rather different life experience involving the entrance of the retarded child into their family, it is reasonable to predict that their subsequent life experiences are also different from families with biological retarded children. Before turning to these families, however, it would be well to briefly review the literature on family reactions to biological handicapped children, as well as prior work in the adoption of handicapped children.

Family Reactions to Biological Handicapped Children

Investigators have traditionally viewed the presence of a retarded child in the family as crisis producing, often inducing life-long stress and distress. The literature is replete with terms such as 'chronic sorrow', Olshansky's (1962) label for the presumably pervasive and enduring reaction suffered by parents of a mentally retarded child. Other writers have focused only on the initial reactions of shock, disbelief, anger, denial, despair, mourning for the fantasied, but lost, perfect child (see Parks, 1977 for a summary of this work), and have suggested that the end of the process comes when parents come to accept the child, become attached to it, and begin to meet its needs as well as those of the rest of the family. If, and when, this final adjustment is made it precipitates a crisis of a different sort, that involved in the reality of caring for a difficult-to-care-for child. Writers have separated these two types of crises by referring to the former as a tragic crisis or a personal values crisis, and the latter as a role organization crisis. or a reality crisis. Existential crisis may be the best label for the

initial reaction since there seems to be general agreement that its components include feelings of despair, meaninglessness, questioning of identity, etc. Reality crisis seems appropriately descriptive of the later reaction.

There seems to be little general consensus in the literature as to how profound and long-lasting the existential crisis is and what parental, child or circumstantial factors operate to either ameliorate or prolong it. For example, Olshansky's proposal that parents of retarded children feel chronic sorrow has little in the way of substantive data to support it. His original paper was an essay based on personal, clinical experience and others have written from a similar perspective (Wright, 1976; Ballard, 1978). Indeed, later work indicates that the greatest distress is at the initial diagnosis of mental retardation and that although stress and sadness do also occur later, they tend to be experienced periodicially rather than continuously (Wikler, Wasow & Hatfield, 1981).

In addition to lack of consensus, there has been a general tendency to treat tentative and unreplicated findings as conclusive and to overstate the negative impact of the retarded child. For example, the now classic work of Farber and his colleagues usually has been cited as indicating a more negative reaction to a severely mentally retarded child than the data warrant. Farber (1959) compared the marital integration of families who had institutionalized their retarded children with those who kept them at home. The only near-significant result he found was that for parents with low marital integration before the child was born (marital prediction score) institutionalizing a boy was associated with

higher marital integration than keeping the boy at home. This finding did not pertain for girls nor for families with high marital integration prior to the birth of the retarded child. Similarly, in Farber (1960) there were no overall significant differences in mean marital integration of parents with a retarded child in an institution and parents with a retarded child at home.

Another of Farber's (1959) findings that has been often quoted and somewhat overemphasized for its negative impact is the effect of a retarded child on the normal siblings. He found that the maternal ratings of personality traits of normal sisters of the retarded are significantly higher if the retarded child is institutionalized. What rarely gets reported however, is that this effect holds only if the retarded child is under 10 and the reverse effect occurs for normal brothers, i.e., their personality ratings are higher if the retarded sibling stays at home. Since none of Farber's work uses nonretarded controls, it is impossible to draw any conclusions about stress and negative adjustment in comparison to what the normative family experiences. Indeed, a number of investigators have questioned, given the clinical nature of many of the studies in this field, the biases of those conducting them and the scarcity of work utilizing comparison groups, whether there is any chronic negative impact on the family of having a retarded child (Friedrich, & Friedrich, 1981, Voysey, 1975; Booth, 1976).

One of the better and more recently conducted studies in this area attempted to compare parents of handicapped children with those of matched,

nonhandicapped children on a number of psychosocial measures. Friedrich and Friedrich (1981) studied 34 families of children who were either mentally and/or physically handicapped and a control group of 34 families matched for family income, maternal age and family size who had nonhandicapped children of a similar age (mean CA ≥ 9 years). Mothers completed five different self-rating scales, including the Holroyd Questionnaire on Resources and Stress which measures 15 different dimensions relevant to families caring for a dependent member (Holroyd, 1974). Friedrich and Friedrich concluded that the mothers with handicapped children reported a less satisfactory marriage, less religiosity and less psychological well-being than the mothers with nonhandicapped children. They reported significantly more child problems such as difficult personality characteristics, social obtrusiveness and occupational limitations: significantly more parent problems such as poor health/mood, excess time demands and negative attitudes, and significantly more difficulties in family functioning such as lack of family integration and limits on family opportunity. Indeed, of 19 different dependent variables measured, only 3 failed to demonstrate significant group differences: Mothers of handicapped children did not report more pessimism, more financial problems or more lack of social support on the Holroyd than did mothers of nonhandicapped children.

In contrast, Gath, (1977) studying only Down syndrome children, found very few differences between their families and families with normal children matched for child age, social class, and family structure. Physical health, psychiatric illness, and family activity were comparable for the two groups. However, there was a significantly higher rate of marital breakdown or serious marital disharmony among the families of the Down syndrome children.

Friedrich (1979) attempted to predict the coping behavior of mothers of handicapped children. Using the Holroyd as the criterion variable, and 19 predictor variables, e.g., severity of child's disability, child's sex, religiosity. marital adjustment, he found only three variables that significantly predicted coping behavior and that accounted for 46% of the -total variance. The most significant of these three was the mother's degree of marital satisfaction and feelings of security in the marital relationship. In addition, less stress was reported by mothers whose handicapped child was at home rather than in an institution and more stress was reported by mothers of a female, rather than a male, handicapped thild. Not only were more severe disabilities not associated with more stress, but, in fact, there was a significant negative correlation between these two variables. The finding relating to marital satisfaction is not surprising and is comparable to what Farber's early work demonstrated. The other findings are not congruent with previous work and although they might be explained on a post-hoc basis (e.g., stressed families are more likely to institutionalize a.handicapped child) they clearly need replication before they can be taken seriously.

Holroyd's own work with her questionnaire has consistently demonstrated that the scale discriminates among different types of caregivers and dependent members. For example, in Holroyd (1974), mothers, more than fathers, reported poorer health or mood, limitations in freedom and personal development. Mothers of retarded children were more concerned about overprotection or dependency problems than mothers of emotionally disturbed children. Holroyd and McArthur (1976) compared mothers of autistic, Down syndrome and outpatient clinic children. The mothers of autistic children reported more



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personal and family problems than mothers of children in the other two groups, but mothers of Down syndrome children did not report more problems than mothers of outpatient clinic children. This last finding is of particular interest, since it suggests, along with Gath's (1977) data, that the reality of caring for a Down syndrome child may not be as stressful as many writers have assumed it to be.

These reality crises, also, may not be either unending or immutable. • For example, Birenbaum (1971), in an interview study of 103 mothers of retarded children, found, as others have done, that the women described many difficulties in both adjusting to the birth of a handicapped child, and to the strain of raising a handicapped child. They also, however, described benefits. One respondent said, "Well, at times I felt like the sacrificial lamb. And at other times I felt very happy. It brought my husband and I very close." Another mother described the satisfaction she received in watching her retarded daughter develop and learn. In response to a question about changes in the situation since the child's retardation was first diagnosed, 75% of the respondents said things were better or much better than before, usually because the child was increasingly able to fit into family routines. Burden (1980) conducted a longitudinal study of 25 mothers who received homebased therapy for their severely handicapped infants. Whereas almost half (46%) of the mothers had been depressed right after the birth of their handicapped child, only 21%, were still depressed two years later. Furthermore, although the author is properly cautious given the nature of the data and the comparison group, there is the suggestion that the mothers who received extra support services showed greater improvement than did the. control mothers.

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Darling (1979) also discusses these themes in her book about 22 families with children having birth defects, most of whom were retarded. She reports that although the initial reactions of guilt and self-pity that follow the diagnosis are usually intense, they are also usually short-lived. For example, one mother said, "As time goes on, you fall in love. You think, 'This*kid's mine, and nobody's gonna take her away, from me!' I think by the time she was 2 weeks old I wasn't appalled by her anymore." (p. 136). Although some mothers reported having a breakdown when the child was young, they all reported an improvement in mood and health that seemed related to their involvement in either formal or informal support groups. Some parents said that they had wanted their handicapped child to die, early on, but all described the gradual growth of love. Darling concludes that although marital and family disintegration may be one consequence of the birth of a handicapped child, her data suggest that the opposite effect is just as probable.

In summary, then, many studies have described the immediate negative impact on the parents of discovering their child is handicapped, an impact which frequently precipitates an existential crisis. Other studies have gone on to look at the way families adjust and cope in the long run to the reality crises of rearing what may be a more-difficult-to-rear-than-normal child. This latter work has frequently found both a positive and a negative effect of having a handicapped child in the family. Positive effects usually described include strengthening marital and family relations; increasing compassion, love, meaning, purpose,

understanding; enhancing life for the sibling. Negative effects are frequently extensions of the reactions during the existential crises, e.g., unresolved guilt, anger, lowered self-esteem, but also include reality demands of time involvement, expense, and extensive and unrelenting physical caretaking. What none of the published work has attempted is to disentangle the adjustment to the existential crisis from the adjustment to the reality crisis. This disentanglement, of course, would be most difficult to accomplish in the biological family where the reality crises begin almost immediately upon the diagnosis of handicap while the family is embroiled in the acute stages of its existential crisis. It is not only a temporal simultaneity, however, which creates the inextricability. Clearly, parents who are guilty, embittered, grieving and angry are not going to perceive and react to reality crises in the same way as parents who are not so suffering. Thus, the realities of caring for a mentally retarded child, for example, may seem far more burdensome to the parent who is still mourning for her/his perfect baby and finds it difficult to form an attachment to the marred substitute that took its place.

Nonetheless, there are methods which should help to differentiate the results of the existential and reality crises. One technique is to study the existential crisis as an independent variable and examine its relationship to the reality crisis. For example, if one could rate the biological family as to intensity and duration of distress following the diagnosis of handicap and then also measure the amount of stress and strain in actually caring for the handicapped child, the relationship between the two might be clarified. To my knowledge, no investigator has used this method.

A second approach is, in a sense, a subset of the first. could locate families who are rearing mentally retarded children and thus would be involved with the reality concerns, but who had not experienced any existential crises following the diagnosis of their child, then the two reactions would be readily separable. Such parents would be highly unusual, perhaps nonexistent, among the biological families of retarded children, but should be very common, indeed, virtually universal, among those families who had adopted retarded children. Such families would have made a conscious and voluntary decision to rear a handicapped child; they would have known about the handicap and have some information about how to cope with it prior to the beginning of their reality concerns. Thus, whatever reality crises adoptive parents experience should be a 'pure' consequence of the reality of caring for a difficult child and not a result of unresolved existential conflicts. The literature on adoption offers a very incomplete response to this issue.

Families Who Adopt Mentally Retarded Children: Previous Work

The need for adoptive parents of handicapped children has been recognized for several decades. Fradkin, writing in 1958, described both the negative, e.g., being rejected for a normal child, and positive, e.g., extreme flexibility, characteristics that might motivate parents to consider adopting a handicapped child. Yet, as late as 1977, Krisheff wrote that essentially no information was available on the attitudes, policies, or practices of agencies regarding the adoption of mentally retarded children. Nonetheless, retarded children are being adopted in

increasingly greater numbers than in previous years. Although there are no accurate national data available in the U.S., some representative data from Great Britain are of interest. Between 1979 and 1981 the British Agencies for Adoption and Fostering, a national clearinghouse for hard-to-place children, reported more than a doubling of the number of retarded children placed through them. More particularly, the number of Down syndrome children placed quadrupled in that two year period (British Agencies for Adoption and Fostering, 1983).

Given, then, that there are families adopting mentally retarded children, do we know from previous work what characteristics, if any, typify those families and whether they experience the difficulties of rearing a retarded child reported by the biological parents of retarded children? The answer is dramatically and resoundingly "no." Although Gallagher (1968) described what should be the characteristics of parents who adopt retarded children, there is very little published literature that examines this issue. Indeed, an extensive bibliographic search uncovered only two studies, published or unpublished, that provided any empirical data.

Gath (1983) described 11 families who knowingly adopted, or long-term fostered, mentally retarded children. Seven of the children had Down syndrome. The parents were older; the mothers' mean age would have been 44 at the time their adopted/fostered child was born. Three of the 11 parents were widowed women; the remainder were married couples rated as having a good quality marriage. Five of the eleven families had fostered children before and two had a biological handicapped children. Eight of the families had biological children and in five of these cases, the children were adult and independent already. None of the 11 mothers



was rated as having significant psychiatric problems. In contrast, 20% of the mothers in a comparison sample of families with biological mentally retarded children had significant psychiatric problems. Indeed, Gath described the foster/adoptive parents as ones who have "unusually strong personalities, stable relationships and an outward-looking attiude combined with a high degree of determination."

De Leon and Westerberg (1980) examined the records of one agency to compare 21 families who had adopted retarded children with 58 families who had adopted nonretarded children over a 3½-year period. They examined nine variables, all of which were adoptive parent characteristics: physical handicap, unusual appearance, religious behavior, experience with children, marital status, educational status, occupational status, working/non-working at time of application, and age. They found that persons adopting retarded children tended to be more unusual in appearance, e.g., over or under weight, severe dental problem; less well-educated; and to have at least one non-working parent. The authors concluded that the people who usually may not be favored by adoption agencies may be the ones most likely to adopt retarded children. They do not speculate as to whether this finding may be the result of agency policy, i.e., giving "less qualified" parents "less desirable" children, or parental self-selection.

Two other studies have examined the adoption of children with medical problems. In Franklin and Massarik's work (1969a, b, c), mentally retarded children were specifically excluded. However, some of their findings may be relevant, particularly those pertaining to the children with severe medical conditions, where extensive rehabilitation and home treatment



may be needed. For example, children with severe medical problems were more likely to be adopted by families where the mot r was over 40, where there were biological children already in the family, and where the families were in a lower social class. It is important to note, however, with regard to the social class finding, that 31% of the families who adopted severely impaired children were in the professional/managerial classes. Indeed, the authors conclude that there are two rather different prototypical adoptive families. One is less well-educated and less achievement-oriented, seeing their child as just a child. The other is highly educated, affluent, very achievement-oriented. This latter family type saw themselves as being motivated by the desire to help a child who needed help.

Wolkind and Kozaruk (1983) also studied the adoption of children with medical problems, but they did not exclude retarded children from their sample. Indeed, of the 84 families that they interviewed, 12 children or 14%, were considered to be either retarded or significantly developmentally delayed at the time of placement. A number of family characteristics of this subset of 12 deserve mention. Firstly, in comparison to the "usual" adopter, they were less likely to be in the professional classes. No family was in the highest social class in Great Britain, Registrar General (RG) 1, and three families were in RG 4, semi-skilled work. Secondly, most of the families had prior familiarity with handicap, either through work or personal experience. This characteristic was particularly true for the families who adopted children whose retardation was definite and likely to be moderate or severe, e.g., Down syndrome. In fact, all of these families specifically wanted to adopt a handicapped child, in contrast to many of the other families who wanted to adopt a child, but were willing to consider a handicapped child.



Some of the above work also looked at the outcome of the adoption. Gath (1983) reports that the foster/adoptive parents of the Down syndrome children in her sample found great rewards in what they were doing and that the children had fewer behavior problems than those who had been institutionalized. Franklin and Massarik (1969b) reported that 71% of the adoptive parents of children with severe medical problems felt that the family had not been adversely restricted or influenced by the child's condition. However, parents of children with more severe medical problems, in contrast to less severe ones, were more likely to indicate the defect as a cause of stress in the family. (1980) reports a similar finding. In his study of 137 mentally retarded adopted children, almost 25% of the families were experiencing serious problems. He also states that this finding is particularly true for the more severely retarded children. His sample size for these categories is very small however, so that his conclusions should be regarded with caution.

In Wolkind and Kozaruk (1983) some specific questions were asked of the respondent parents that pertained to the success of the adoption. Raters were able to categorize the adoption outcome as being at one of three success levels: 1) highly successful, would definitely do it again; 2) uncertain success, some regrets about doing it; and 3) definite regrets, would not do it again. Of the 12 families described above, 11 were scored as category 1 and one was scored as category 2. Thus, these families viewed the adoption of their children in a very positive way.

In summary, then, although there is very little substantive work by others on the adoption of retarded children, there are suggestions that people who adopt such childen are: 1) usually familiar with



handicap; 2) not as highly educated as other adopters; 3) experienced child rearers; 4) frequently motivated to adopt a handicapped child, specifically. Other characteristics have not been systematically studied. In addition, all three studies which have looked at outcome have found that the large majority of parents view the adoption as successful and the relationship between parent and child as positive.

Families Who Adopt Mentally Retarded Children: The Present Study

The present study is an outgrowth of this previous work. Its major objectives were to 1) describe demographic characteristics, e.g., age, educational level, social class, religious affiliation, etc. of families who adopt mentally retarded children; 2) explore the pre-adoption motivation of the parents, i.e., how and why did they come to be adoptive parents of retarded children; and 3) assess the post-adoptive adjustment of the families.

Subjects

The subjects were 20 British families who had, among them, adopted 23 retarded children. Characteristics of the family members, including those of the adoptive children, are presented in Table 1.

Insert Table 1 about here

These families were identified through the adoption agencies which had been instrumental in placing the children. Twenty-one different agencies were involved, each placing from one to four children in the sample.

All 20 families contacted agreed to participate, but the sample cannot



be considered either random or unbiased. Only agencies with a reputation for placing handicapped children were contacted. Since more severely handicapped children are usually more difficult to place, the sample consists almost entirely of children who are retarded because of a definite organic etiology. As can be seen from Table 1, only two children did not receive an absolute diagnosis of either chromosomal/genetic or other organic etiology and even in these two instances there were family and medical histories that were not inconsistent with organic involvement, e.g., epilepsy.

The children went to live with their adoptive families when they were, on average, 67 months old. This mean, however, maske a wide range of 5-185 months. Similarly; although the children were, on average, 103 months at the time of this study, their ages ranged from 18 to 209 months.

Method

All interviews, except one, were done in the homes of the adoptive families. All 20 mothers were interviewed either alone or with the fathers. The present report, however, will focus only on data from the mothers.

The interview was semi-structured, focusing on three primary areas of interest. The first section was concerned with pre-adoption motivation and how the mother or family had made the decision to adopt and how that decision led to the adoption of the target child or children. The second section dealt with background of the family, particularly the parents and their extended family. The third section contained many detailed questions about the impact of the adopted retarded child on family functioning. The completion of the interview schedule itself



took from about 1½ hours to 5 hours, depending on the number of target children in the family, how elaborative the respondent(s) was and how many interruptions were necessary. Although some coding of the interview schedule was done at the time of interview, with the permission of the respondents all interviews were tape recorded and coding also done from tapes.

Following completion of the interview schedule, the respondent(s) were asked to complete two questionnaires. One, an adaptation of that designed by Farber (1959), consisted of 10 multiple-choice questions, assessing functioning of the respondent following the placement of the child in the family. This short questionnaire was completed by respondents immediately following the interview. The second questionnaire was the Questionnaire on Resources and Stress designed by Holroyd (1974) to assess functioning in families caring for a handicapped, dependent member. It consists of 285 true-false statements and was analyzed along the 15 different dimensions suggested by Holroyd. These questionnaires were left with the respondents along with a stamped, addressed envelope for return. All the families completed and returned them.

Results and Discussion

Demographic and background characteristics. Social status was measured by the Registrar General's index of occupations. Father's occupation was used except in the four instances where the adopter was an unmarried woman, in which case her occupation was used. The Registrar General system has six divisions, RG 1 and 2 being professional; RG 3 being skilled work either non-manual (3 NM) or manual (3 m); RG 4 being semi-skilled work; and RG 5 being unskilled work. As in other adoption studies (Wolkind & Kozaruk, 1983; Raynor, 1980) the majority of the families were in RG 1 or 2 (60%);



Although this sample is more professional than the British population in general, it is also less skewed toward RG 1 than the general adoptive population. Only 1 of the 20 families (5%) was in RG 1, whereas other adoption studies report much higher percentages (e.g., Raynor, 1980 = 22%). As would be expected, given the occupational status of the adopters, educational level was also high. In England, a three-tier classification system is most appropriate to categorize education: (1) School leaving without passing any examinations; (2) Certification by some examination system (there are several); (3) College or university education. Using this tripartite system, 75% of the mothers had passed some school examinations and 60% had some college or university training. The fathers were similarly well-educated with 63% of them having passed school examinations and 56% having some college or university training.

All of the families lived within 125 miles of London, although the type of area varied with 10% living in urban, 40% living in suburban and 50% living in rural areas. Sixty percent of the adopters owned the home they were living in.

The majority of the respondents described their religious affiliation as Church of England with 55% of the mothers and 56% of the fathers so describing. Roman Catholicism was the next largest group, with 20% of the mothers and 13% of the fathers so affiliated. Three couples preferred the designation Christian to any denominational affiliation; one couple was a member of the Jehovah's Witnesses church and one couple said that they had no religious affiliation.



Most families had either work or personal experience and familiarity with handicap. Three of the 20 families had had a biological handicapped child and one family had previously adopted a "normal child" who turned out to have a handicapping condition. In 15 of the families either one or both parents had work experience with handicapped persons, <u>e.g.</u>, nursing, special education. In only three cases was there neither a personal or occupational familiarity with handicap.

As can be seen from Table 1, 8 of the 20 families or 40% had at least one living biological child. However, in the case of one family, those children were the mother's by a previous marriage. This adoptive couple had no biological children with each other. Including them and the four unmarried women, 13 adoptive parents had no biological children.

Pre-adopt on motivation. The motivations to adopt were various.

Eleven of the twenty adopters, or 55%, had specifically wanted a handicapped child. Of these eleven, five had no biological children, although one couple had already adopted two other, not previously handicapped children. Of the nine adopters who did not initially seek a handicapped child, eight, or 89%, were childless, in contrast to the 45% childless adopters who wanted a handicapped child from the beginning. The eleven adopters who initially wanted to adopt a handicapped child had many different idiosyncratic reasons for so wanting. One mother had worked in a residence for physically handicapped children 15 years prior to her child's placement and had vowed that if ever in a position to do so she would adopt such a child. The child placed with her was both physically and mentally handicapped.



Another couple both worked as nurses' aides in an institution for the retarded and decided that they specifically wanted to adopt a Down syndrome child, because they so enjoyed the Downs' residents with whom they worked. One couple, with two biological children, had talked for several years about their desire to provide a loving family life to a child who desperately needed one. Then the mother saw a newspaper advertisement for a particular handicapped child, called the adoption agency to make an inquiry, and although that advertised child was already unavailable eventally adopted a different retarded child.

The eight childless adopters who did not seek a handicapped child initially had a primary motivation of wanting a family, but in contrast to many who want a family, were willing to consider a retarded child as a family member. Sometimes this willingness clearly came from a familiarity with handicap, sometimes from a religious or world-view of the importance of nurturance for all humans, and sometimes from a seemingly naive or matter-of-fact perception of the child as "not all that different from normal."

Religion was a motivating factor for a significant minority of adopters.

Thirty percent of the adoptive mothers mentioned it as an important influence. These same mothers also attended church at least once a week and saw themselves as more religious than the average Briton.

Post-placement adjustment. Although the semi-structured interview contained several dozen questions relating to post-placement family functioning, only the results of the two global assessments of the placement will be considered here: 1) All things considered, has ______'s adoption



worked out: Better than you expected, about as well as you expected or less well? and 2) Thinking back over your entire experience with-, and all the good times and the bad times - if you had it to do over again, do you think you'd adopt____ . would you not adopt him/her, or are you unsure? Each of these questions was coded on a 3-point scale with 3 being the best outcome category and 1 being the worst. Of the 23 children placed, 14, or 61%, received a total score of 6 indicating that their mother thought that the adoption had worked out betterthan expected and she would do it again. An additional four children received combined scores of 5, all with a 2 on question, 1 (Adoption had worked out as well as expected.) and a 3 on question One mother said she had no expectations and thus couldn't answer. question 1, but she gave a 3 on question 2. Thus, it can be concluded that the adoptions of 19, or 83%, of the children were definitely successful. In two of the remaining four cases, the combined scores were only 2, meaning that the adoption was worse than expected and, in fact, the family would not do it again. Indeed, in one of these families the placement was disrupted and the child had left the home just prior to the interview. Interestingly, in both of these "worst" cases the children were over 10 at the time of placement. The remaining two cases are less extreme. In both families, the target child was the second of two mentally retarded children who had been adopted, and the adjustment ' to the first child had been fine with the adjustment to the second, more recently placed, child, being somewhat more problematic. Both mothers said that the placement was working out less well than they had anticipated, but neither mother said that she wouldn't do it again. Also, both mothers indicated that they thought the adjustment would improve in time. '



Results of responses to the Farber questionnaire also show remarkably little difficulty in coping with the problems of a handicapped child. In fact, for 35% of the 23 children, mothers indicated that no change had occurred on any of the 10 variables (e.g., patience, worry, anger, marital relations) queried in this form: For the other families there were more changes in the positive direction than in the negative. Seventy percent of the 23 forms had no negative changes indicated.

Results of the Holroyd questionnaire are a bit more difficult to interpret without a comparison group. However, Holroyd has made means available for a number of different groups, and although these groups can certainly not be considered controls since the children differ on a number of characteristics from the children in the present sample, including age, culture and possibly, social class, it is informative to examine the pattern of differences. Table 2 presents the means for all 15 scales of the Holroyd for the 23 retarded children in the prsent sample along with the means for two comparison groups from Holroyd's research, normal controls and developmentally disabled (DD) ten-year-olds.

INSERT TABLE 2 ABOUT HERE

As can be readily seen from Table 2, the present sample much more closely resembles the normal controls on eight of the fifteen scales, Scale 1, 2, 3, 4, 8, 9, 10 and 12. On four scales, the means of the



present sample are below but close to the means of the DD sample. On two scales, <u>Pessimism</u> and <u>Physical Incapacitation</u>, the means for the present sample, are actually higher than the means for the DD sample. Of particular interest is that most of the eight scales on which the present sample resembles the normal controls represent attitudinal and psychological variables, <u>e.g.</u>, poor health/mopd; negative attitude toward index case; lack of family integration. In contrast, the six scales on which the present sample more closely resembles the DD sample, reflect more reality oncerns, <u>e.g.</u> physical incapacitation, occupational limitations, difficult personality characteristics.

Thus, one is wont to speculate that adoptive parents, like biological parents, experience some difficulties in rearing mentally retarded children but, that 1) these difficulties are not experienced in as psychologically damaging a way for them and/or 2) their psychological mood and attitudes are different as a result of the very different circumstances surrounding the entrance of the retarded child into the family. As one mother articulated when talking about the differences in the reaction of biological and adoptive families, "When you're talking about fostering or adopting a mentally handicapped child, it is a completely different relationship. You chose the child; you took it because you felt you could do something for it, whereas the poor mother is presented with this child...completely different altogether."

Summary, Conclusions, and Implications

In symmary, then, the work suggests a number of tentative conclusions as well as a number of interesting areas for further exploration. The

type of family who is likely to adopt a mentally retarded child: 1) is familiar with handicap; 2) is more likely to be middle-class than the average person, but less likely to be of the highest social class than the average adoptive family; and 3) has a variety of reasons for wanting to adopt which may include biological infertility, religious conviction, and personal/professional experience with handicap. The present numbers, however, are too small and the sample too nonrandomly selected to state these conclusions firmly.

Many adoptive families do experience reality crises, or, at least, difficulties, although most of them seem to cope with these problems quite well. Of course, since no direct comparison has been made between adoptive and biological families who are matched on family and child characteristics, this conclusion is very tentative. An additional reason for being tentative about the conclusions is that the children in the present sample were only in their adoptive homes, on average, 17 months, and 11 children or 48% were still under 5 years old at the time of interview. Thus, it is a young and recently adopted sample. Others (e.g., Wikler, 1981) have suggested that when the retarded child enters puberty and young adulthood, the family is likely to experience stress as there are new reality crises with which to cope. Clearly, the present study, time-bound as it was, could not assess the probability of such difficulties.

The present work, then, describes families who have chosen to rear retarded children and has characterized them in terms of demographic and motivational characteristics. It also suggests that they may cope better than the biological families of retarded children. However, even if the latter conclusion remained true after additional research, its



cause is not patently obvious. Do adoptive families have an easier time because they do not suffer existential crises or are they, to begin with, very special families, high on such characteristics as family integration, commitment and responsibility. Clearly, further investigation is necessary. We need to study more families who adopt mentally retarded children as well as compare them with matched families who have biological retarded children. These comparisons, to yield maximally fruitful data, should examine age of adoptive child and length of placement as predictor variables. Longitudinal as well as cross-sectional data are needed. It is only such carefully controlled comparison which will be able to disentangle the effects of the existential crises from the reality crises, and begin to assess a cause-effect relationship between the two.

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TABLE 1 Characteristics of Adoptive Families

Family #	Child Diagnosis	Child Age (in mos.) at Placement/Interview	Marital Status of Mothers	Living Biological/ Previously Adopted Children
1	Brain damage	120/123	s	0
2	Down syndrome	97/137	S	0
3	Brain tumor	47/58	M	5
4	Cerebral palsy	172/179	. s	0
5	EMR; epilepsy	118/131	M	2
6	Brain damage .	25/31	M	2 (adopted)
. 7	Down syndrome	1,4/21	М	2
8	Prader-Willi	66/79	⊸. W	4 (adopted)
9 .	EMR	157/169	M	0
10A ~ 10B	Down syndrome	8/44 60/72	M	0
11 -		45/54	М	2
12 ·	11 11	10/18 .	М	2
13	Cornelia de Lange	172/209	М	0
14	Down syndrome	31/44	М	2
15	`Cerebral palsy	131/144	М	0
16A 16B	Spina bifida Brain dmage	88/122 82/92	S	0
17	Down syndrome	11/17	. м	0
1,8	11 11	5/43	М	0
19A 19B	11 11	5/49 11/24	M •	. 3
20	11 11	185/193	. M	4 .



Means of Holroyd Questionnaire for Present Sample

TABLE 2

and Two Holroyd Comparison Groups

	Glidden: Adopted MR	Holroyd: Normal Controls	Holroyd Developmentally Disabled
N X Age	23 8.6	21 10.4	143 9.8
Scale,			** *** *** *** *** *** *** *** *** ***
1	1.35	_ 2.05	4.95
1 2	4.22	3.67	5.53
3	5.25	4.24	10.98
4	3.88	3.14	6.17
5	4.06	2.52	4.45
6	2.87	2.24	3.50
7	3.79	2.71	3.53
8	2.88	2.86	5.23
9	0.57	0.43	1.80
10	3.45	2.57	5.49
" 11	3.61	1.00	2.81
12	0.91	0.52	2.47
13	3.13	1.05	3.43
14	1.91	0.48	2.41
15	12.69	3.38	15.33

Scale Summary

- 1. Poor Health/Mood, e.g., I get upset with the way my life is going.
- 2. Excess Time Demands, e.g., I can go visit friends whenever I want.
- 3. Negative Attitude Toward Index Case, e.g., I don't mind when people look at _____.
- 4. Overprotection/Dependency, e.g., It is easy to do too much for



5.	Lack of Social Support, e.g., My family understands the problems I have.
6.	Overcommitment/Maryrdom, e.g., I have too much responsibility.
7.	Pessimism, e.g., cannot get any better.
8.	tack of Family Integration, e.g., Our relatives have been very helpful.
9.	Limits on Family Opportunity, e.g., The family does as many things
÷	together now as we ever did.
10.	Financial Problems, e.g., We can hardly make ends meet.
11.	Physical Incapacitation, e.g., can walk without help.
12.	Lack of Activities for Index Case, e.g., It is easy to keep
	entertained.
13.	Occupational Limitations for Index Case, e.g., The special opportunities
	needed by are available in our community.
14.	Social Obtrusiveness, e.g., The community is used to people like
15.	Difficult Personality Characteristics, e.g., is very
i., .	inritahla